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ABSTRACT

Discussed in the report on planning for services to deaf-blind persons are the impact of the 1963-65 rubella epidemic on service delivery, the need for service system information and control, prevention of rubella as a cost-effective alternative to after care, estimates of the size of the 1980 deaf-blind population, and the projected (1980)cost of serving the deaf-blind. Cited is the need for information on such topics as the prevalence and needs of the deaf-blind population (both the young and persons older than age 21); the degree of hearing, vision, and mental impairment; the cost of alternative service; and the effectiveness of current services and of coordination of existing programs in order to provide an integrated service system. Projections for 1980 demonstrate the necessity of current action to prepare programs for adult residential care and vocational services for teens and young adults. Noted are factors which may affect service costs, such as the effect of inflation on the level of government effort. (LH)

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PLANNING FOR 1980

by

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SERVING THE DEAF-BLIND POPULATION:

PLANNING FOR 1980*

Garry D. Brewer, James S. Kakalik

May 1974

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I. INTRODUCTION

While rubella is only one of many causes of deaf-blindness, the rubella epidemic of the mid-1960s has contributed untold pain, sorrow, and expense for this society: including more than a quarter of the approximately 4400 young deaf-blind persons who have been identified, and tens of thousands of children with less severe but very major handicaps. This much larger than average cohort of handicapped contains children who are all approximately the same age, and this fact has created major problems for the service system in responding to their needs as the children progress from needing medical and preschool services to needing very special types of education, to perhaps needing vocational, residential or other services, when they become older teens in 1980. The results of that epidemic were not all tragic, however. It did have the positive effects of galvanizing government officials into action to create a rubella vaccination program, the Regional Centers for Deaf-Blind Children and the National Center for Deaf-Blind Youths and Adults; those three programs should result in better services for future children and for deaf-blind children and adults, including those whose handicaps were not caused by the rubella epidemic.

The much larger than average cohort of deaf-blind children, as it progresses upward in age, punctuates some very major problems of the fragmented system serving handicapped children and youth; e.g., underdeveloped prevention services; lack of information needed for effective planning; and failure to mobilize far enough in advance to meet known future needs of the deaf-blind handicapped population.

In this paper, we briefly consider the planning required to meet the needs of young deaf-blind persons in 1980; we discuss the need for information about and control of the service system; note the need to improve identification programs, especially for older deaf-blind persons; illustrate the humanitarian and economic desirability of prevention; and we make projections of the number of young deaf-blind persons and the cost of serving them in 1980.

For a much more detailed description of the system serving handicapped persons, documentation of its problems and numerous recommendations for improvement, refer to our Rand Corporation reports, *Services for Handicapped Children: A Program Overview*, R-1220-HEW (May 1973); and *Improving Services to Handicapped Children*, R-1420-HEW (May 1974).

II. SERVICE SYSTEM INFORMATION AND CONTROL

Planning for services to deaf-blind persons is severely hampered by a lack of relevant information and a lack of coordination and control of the service system due to its fragmented nature. Information on the prevalence and needs of deaf-blind persons over the age of 21 years is practically non-existent; nationally available data on younger deaf-blind persons is much better but still deficient. For example, data on the nature of the "deaf-blind" person's degree of hearing and vision impairment, degree of functional sensory ability, degrees of other types of functional ability, and presence and degree of additional handicaps--such as mental retardation--may be known to professionals serving the individual, but have not been fully aggregated nationally for planning purposes. Work on the costs of alternative service mechanisms is lacking, and information on the effectiveness of services is severely deficient. Without well developed planning information linking the deaf-blind people in need of services with the many different groups of officials responsible for making policies, the appropriate services cannot be adequately planned for and made available. Deaf-blind children, perhaps more than other handicapped children, require more, more specialized, and usually more expensive services. The nature of these services is such that better planning is required since these services are not normally in high demand and hence are scarce. Due to recent federally sponsored efforts, information has improved markedly, and will soon improve more, but there is still a long way to go.

The young deaf-blind population has been relatively more fortunate than the handicapped population in general with respect to the institutionalization and federal funding of Regional Centers for Deaf-Blind Children throughout the nation. The Regional Centers are intended to identify deaf-blind children and offer comprehensive diagnostic and evaluative services, maintain a registry, develop consultative and training programs for both parents and service personnel, develop new programs and services where they are needed, and coordinate services offered by other existing agencies. The Federal Government also funds a National Center for Deaf-Blind Youths and Adults. The National Center is intended to provide comprehensive services through residential facilities, provide consultative aid to other organizations serving deaf-blind persons, demonstrate methods of service, train personnel, and conduct research on services to the deaf-blind. Federal creation and support of these Centers is justified due to the very low incidence and special needs of the deaf-blind population, which means that individual states generally have too few of them to mount an effective program providing the specialized intensive and comprehensive services they need. Even with interstate regional centers, however, we understand it has sometimes been difficult to obtain highly qualified staff for the service programs because the programs are expanding faster than new professionals are being trained.

In their study of information system requirements for the Regional Deaf-Blind Centers, EXOTECH Systems, in June 1971,* provided some valuable

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*EXOTECH Systems, Inc., *An Information System for Regional Centers for Services to Deaf-Blind Children,* BEH/OE/DHEW, Contract No. OEC-0-70-4923, Washington, D. C., June 30, 1971.

insights into the information requirements and problems of the deaf-blind population. According to EXOTECH, information about this most severely handicapped subset of the population in 1971 was "by any standard poor in quantity and low in quality." The study made positive recommendations about what might be done to improve matters. A Deaf-Blind Center Information System was advanced as a prototypical design for not only the deaf-blind, but for all handicapped persons at some future point in time.

With respect to the system serving deaf-blind children, certain qualitative observations are possible from the information, coordination, and control points of view. The extra service burden represented by the unexpected addition of the 1963-1965 rubella cohort is easily seen as a much heavier than normal load or disequilibrating force. There is not one integrated service system, but rather a number of system fragments. Because of this structural fragmentation--and inadequate information, coordination, and control-- the system is moved to respond in piecemeal fashion with the result that the added service load is actually sensed by first one fragment and then another in the overall system. And segments of the service system sometimes do not sense the heavier load sufficiently in advance to allow the development of added service capacity and trained personnel.

For vocational and other services required by teenagers and young adults, there is still time to prepare for the added load, but the education system has already been seriously impacted by these children.

Doctor and Davis make several pertinent observations about the impact of the rubella cohort when it came into contact with the educational system.* Among other points, the generally different character of the population, having as it did a high proportion of multiple handicapped and sensory impaired children, was not appreciated. The learning problems demonstrated by this population were far different from those the system had learned to cope with in terms of the polio afflicted cohort of some 10 to 15 years earlier. The polio cohort was more like a "normal," i.e., non-handicapped, cohort in terms of its educational needs than was the rubella cohort.

The question, with respect to all the fragments of the system not yet seriously affected, is what is being done *now* in anticipation of the known but unrealized need for service? The question, with respect to those fragments of the system most heavily loaded by the cohort or where the cohort has already passed on through, is what adjustments are being planned to change the level of services currently being delivered to find and serve those coming along who in the past would not have received services, e.g., increasing attention to finding more children and serving those who are less severely handicapped, or decreasing the level of services back to a steady state reflecting the expected number of seriously impaired children who will in the future require services? For instance, some component of service demand will doubtless be chronic, and

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*Pourie Vaux Doctor and Ferne E. Davis, "Educational Impact--The 1964-1965 Rubella Epidemic in the United States," *American Annals of the Deaf* (February 1972), pp. 11-13.

for children in that component one might work to provide full coverage to all who can be found. Another component of service demand will probably be recurring, as in the case of another epidemic (a decided possibility given the dearth of sustaining rubella prevention services currently being delivered) or some unknown horror that might render a portion of an unborn cohort deaf and blind. Finally, some component of today's demand, a demand generated by the extraordinary load of the 1963-1965 rubella cohort, is genuinely regarded as "non-recurring," and once that proportion has been served, service resources no longer needed can be reallocated (much as was the case with polio research resources in the post-Salk era).

Unfortunately, these rather obvious adjustments may not take place given the poor control evident in the present system. The Regional Centers are a step in the right direction, but they do not control the majority of the service system. The nation may continue training elementary-level special education personnel for the deaf-blind when actually more personnel to help with teenaged and adult services are needed in the future. And most painful of all, the system may not have "learned" very much from the experiences generated by the present rubella cohort, for use in some subsequent disaster; and the proverbial wheel will once again come rolling off the drawing boards at some time in the future.

We need to concentrate especially on means to increase lead time or advanced planning and preparation for future service needs. Short or no

lead time situations are undesirable for several reasons. Unanticipated problems tend to produce solutions outdated before they are implemented, e.g., solving yesterday's problems, or solutions that require far more resources than would have been necessary had there been adequate preparation. With increased lead time, those responsible for a system may work out better, more appropriate, or less costly solutions in advance. Resource allocation decisions take time; with insufficient lead time, resources are more likely than not to be inefficiently and ineffectively allocated--poor allocations based on poor or non-existent feedback of information about the actual situation.

III. AN ALTERNATIVE TO AFTERCARE

Since the topic of this paper is planning for service to deaf-blind persons in 1980, it is appropriate to consider prevention as an extremely desirable alternative to serving persons after they become deaf-blind. Not all cases of deaf-blindness can be prevented, but rubella is an excellent example of a major cause that can be prevented, and prevented very economically in relation to the high costs of aftercare. Yet current rubella prevention programs are insufficient and flagging.*

It took a major epidemic in the mid-1960s to force official attention to focus on the case of rubella, but in the absence of subsequent catastrophes, maintenance of this attention and related activity has waned. Not only does it appear to take a human crisis to galvanize system-level attention to a specific problem, but the maintenance of attention is not assured in the absence of other crises.

The importance of long-term maintenance of preventive activities is easily stressed in a simple cost exercise designed to relate prevention costs to service costs for handicaps resulting from inadequate prevention. The rubella epidemic of 1963-1965 left an estimated 20,000 to 30,000 handicapped children in its wake, a tragedy that society will be paying for in many significant ways for years to come.** In his analysis,

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*See Chapter 6 of Rand Report R-1420-HEW (May 1974), for several recommendations for improvement.

**J. L. Sever, et al., "Epidemiological Observations of Rubella in the Collaborative Perinatal Research Study," *Proceedings, International Conference on Rubella Immunization* (Stockholm, Sweden: February 18-20, 1969).

Donald Calvert estimated the special educational costs alone associated with the impaired subset of the epidemic population.* We have made our own more conservative estimates based on special education expenditure data accounting for the discounted incremental costs about the cost of regular education. As can be seen from Table 1, Calvert's and our estimated special educational costs differ significantly; however, even taking our intentionally conservative estimate as a basis of comparison, there is a striking difference between the $202 million in increased special educational costs due to that one rubella epidemic and the $41.6 million total authorized under the Rubella Immunization Program.** And we have not even considered increased costs of services other than special education in the calculation, not to mention the degradation of quality of life inflicted by the handicap.

The urgency of such preventive programs is manifest if we look only at the high annual cost associated with the special education for deaf-blind children: from $12,000 to $14,000 per child.*** For the estimated 1250 deaf-blind children resulting from the 1963-1965 rubella epidemic alone, this represents an annual outlay of about $15 million (using the low estimate).

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*Donald R. Calvert, *Report on Rubella and Handicapped Children*, Department of Health, Education and Welfare, Bureau of Education for the Handicapped, Washington, D. C., May 1969.

**Section 314(e) of P. L. 89-749.

***The low estimate is that used by California's School for the Blind in their deaf-blind program, and the high figure is that reported by Calvert for Massachusetts' Perkins School for the Blind's program in 1969. (No allowance for inflation is made.)

Table 1

ESTIMATED COSTS FOR 13 YEARS OF SPECIAL EDUCATION OF HANDICAPPED CHILDREN FROM THE RUBELLA EPIDEMIC OF 1963-1965[a]

Handicap	Number	Undiscounted Total Cost: Calvert Estimate	Discounted Total Incremental Cost: Rand Estimate[b]
Visually impaired	5,500	$350,250,000	$35,500,000
Hearing impaired	12,000	468,000,000	77,400,000
Deaf-blind	1,250	227,500,000	81,000,000
Retarded/crippled	1,250	48,750,000	8,100,000
Total	20,000	$994,500,000	$202,000,000

[a]Source: Donald R. Calvert, *Report on Rubella and Handicapped Children*, Department of Health, Education and Welfare, Bureau of Education for the Handicapped, Washington, D. C., May 1969.

[b]Note: Rand estimates are based on expenditure data contained in Chapter 8 of Rand Report, R-1420-HEW, May 1974. Thirteen-year costs are discounted at 8 percent to time of birth.

The messages from this example and discussion are clear: rubella can be prevented; rubella-caused handicaps are expensive; prevention is decidedly cost-effective; and attention to the rubella immunization program is flagging, with potentially tragic and costly results. The main point of this illustration is that in planning for services for deaf-blind persons in 1980, attention should be paid both to serving those already handicapped and to those who might in the future become so if appropriate measures are not taken.

IV. YOUNG DEAF-BLIND POPULATION PROJECTIONS: 1980

The population of identified young deaf-blind persons is projected to grow from a total of 4414 in the year 1973 to perhaps 5400 in the year 1980. Table 2 gives a breakdown by age. The 1973 data for the cohort aged 3 through 18 are thought to be of relatively high quality due to efforts of personnel throughout the country in the Regional Centers for Deaf-Blind Children. However, we suspect that the number of known deaf-blind children less than age 3 and adults over age 18 is relatively low due to the lack of identification of persons in those age groups.

In looking at the 1973 data for the relatively well-identified cohort aged 3 to 17, note the peak in the population in the upper-elementary school ages due to the rubella epidemic in the mid-1960s; and also note that the number of identified young deaf-blind persons not born in rubella epidemic years is relatively constant at about 140 per year (an average of 138 per year for children now aged 3 to 5, and an average of 142 per year for children now aged 12-17 years). In making our projections to the year 1980, we assumed the following: the quality of infant and adult identification programs would not improve markedly; the 1973 identified population aged 3 or above would age the seven years to 1980 with almost no deaths (note that only 123 of the identified young deaf-blind persons are over age 21); the number of identified deaf-blind children aged 0 to 2 in 1980 will be approximately the same as it is in 1973; and the number aged 3 to 9 in 1980 will be the approximately 140

per year that now prevails for young persons not born in rubella epidemic years. These projections to 1980 thus assume no major new rubella epidemics or other disastrous events that will cause an abnormally high number of persons to be deaf-blind, and they also assume no major progress in the prevention of deaf-blindness. Given the current rubella vaccination program that has protected many but left many others unprotected, it seems most likely that this major cause of deaf-blindness will be partially controlled but still a menace in 1980. Of course, all projections into the future are exercises in predicting the unknown and are subject to uncertainty. In this case, we feel that the 5400 estimate for young persons is the most likely number, but a lower bound would be the currently identified 4400, and 7000 would be an upper bound unlikely to be exceeded without the creation of a comprehensive identification program for adults. That upper bound of 7000 might be reached if, for example, we have another major rubella epidemic between now and 1980.

The change in the age distribution between 1973 and 1980 is marked. As can be seen in Table 2, the number of children of elementary school age declines sharply while the number aged 15 to 21 nearly triples and the number of young deaf-blind persons identified over age 21 goes up seven-fold. The clear implication is that adult residential care and other service programs for teens and young adults, such as those concerned with vocations, must begin to act now to be ready to serve the rapidly growing known teen and young adult deaf-blind population in 1980.

In planning for services in 1980, it is also necessary to consider the various degrees of handicap within the overall young deaf-blind

Table 2

THE 1973 AND 1980 YOUNG DEAF-BLIND POPULATION BY AGE

Age Range (years)	Number Identified 1973[a]	Projection of Number, 1980[b] (to nearest 100)
0-2	60	100
3-5	415	400
6-8	803	400
9-11	1438	400
12-14	413	700
15-17	439	1200
18-21	315	900
21+	123	900
Unknown or unreported age	408	400
Total	4414	5400

[a]Source: Robert Dantona, Coordinator. Center and Services for Deaf-Blind Children, "Demographic Data and Status of Services for Deaf-Blind Children in the United States," Bureau of Education for the Handicapped, HEW, Washington, D.C., April 22, 1974.

[b]See text for our method of projection.

population. Some are both totally blind and profoundly deaf, but many have at least some degree of hearing or vision. Some have only sensory impairments, but many have other handicaps such as mental retardation. Given the poor quality of available data on the degree of deafness and blindness and the presence of other handicaps, estimates of the fractions of the 4414 young deaf-blind persons possessing varying degrees of handicap must be based on subjective expert opinion rather than on hard data. Benjamin F. Smith, the Director of the Perkins School, has ventured that approximately 60 percent to 75 percent are "middle trainable and below" in terms of what he calls "practical functioning levels," approximately 15 percent to 25 percent are "upper trainable though lower educable," and approximately 5 percent to 10 percent are "middle educable and above."*

Using the optimistic end of Smith's percentage ranges, of the projected 5400 identified young deaf-blind persons that may be identified in 1980, only 500 would be middle educable or above, while 1400 would be upper trainable though lower educable, and 3500 would be middle trainable or below in practical functioning levels. Of course, for an individual handicapped person, "practical functioning" is a complex scale having many different dimensions. The three crude categories of practical functioning used above serve only to give necessary overview information about the young population. For planning to meet the service

*Benjamin F. Smith, "Potentials of Rubella Deaf-Blind Children" (Watertown, Massachusetts: The Perkins School, May 1974).

needs of an individual, in-depth personal evaluation of the many different components of "practical functioning" must be made.

We have not ventured any estimate of the size of the older adult and geriatric deaf-blind population due to the dearth of data on the subject. While the majority of young deaf-blind persons have probably been identified by the ten Regional Centers for Deaf-Blind Children, the majority of older deaf-blind persons are not identified. Two counteracting forces make it difficult to make estimates of the size of the older deaf-blind population. Simply applying the prevalence rate for the young to make estimates for the older population would mean the total deaf-blind population was 2 1/2 times as large as the young deaf-blind population (since the total U.S. population is about 2 1/2 times as large as the population aged 0 to 21). However, that simplistic approach is likely to be highly inaccurate since the death rate for multiple handicapped persons is probably higher than that for normal persons, and since it is well known that the prevalence of hearing problems in the population increases with age, as does the prevalence of vision problems. Without better data, we cannot say with any reasonable accuracy how many older deaf-blind persons exist, and what it would cost to serve them.

V. COST OF SERVING YOUNG DEAF-BLIND PERSONS IN 1980

Estimates of the size of the 1980 young deaf-blind population are one of the more accurately predictable factors affecting the overall cost of service. Perhaps the most important unpredictable factor is the level of effort government will chose to make in providing service to deaf-blind persons. Will government elect to spend, say, $5000 per person, per year on the average and thus be able to provide only residential care for those in institutions and minimal services to those whose daily living expenses are privately financed? Will government elect to spend, say, $10,000 per person, per year and thus provide services of modest quality? Or will government elect to spend the perhaps $15,000 per year, per person on deaf-blind children and youth needed so they can approach the maximum of their potential ability? Note that if the inflation rate averages 5 percent for the next seven years, agencies that today are spending $12,000 to $14,000 per year, per child for the higher quality services must spend approximately $16,000 to $19,000 in 1980 to buy the same services.

In aggregate terms, if the projected number of 5400 young deaf-blind persons were identified and served in 1980 at an average cost per year of $5000, then the annual expenditure rate would be approximately $27,000,000. If an average of $10,000 were to be expended per person, then the annual expenditure rate would be $54,000,000. If an average of $15,000 were expended per person, then approximately $81,000,000 per year would be required in 1980 for services to young deaf-blind persons. Yet, that much is probably required per year, at least during the years when

children and youth need to be educated, if this segment of our population is to approach its maximum potential level of ability. And nearly all of those who have been identified are less than 21 years old. The needed expenditures would be still higher if society elected to identify and provide special services to deaf-blind persons in the older adult and geriatric population.

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